



# Breaking Ground

## Breka Takes Control of Her Life, Reaches for Goals

**M**y name is Breka Moore, and I live in Milan, Tennessee. When I was in elementary school, I was put in special education classes because I had a learning disability. Ever since I was in school, I tried to avoid doing things like reading out loud because I didn't want the other kids to make fun of me. Every day when I went to school, I wanted to cry because I didn't want to be different. I wanted to be smart like my friends. As the years passed, I had to realize that I was different.

When I got to high school, I wanted to learn how I could make a difference in my life. I really didn't understand what that meant until I attended the Tennessee Youth Leadership Forum (YLF) a year ago at Vanderbilt University. YLF is sponsored by the Tennessee Council on Developmental Disabilities. At YLF, I learned that if I want to make a difference in my life, I can't be afraid to speak out to let people know that no matter what kind of disability I have, I can overcome anything. I learned that no one should let a disability control one's life. I took control of mine with the support and determination from the speakers, delegates, and the counselors at YLF.

While I was in high school, I always dreamed of getting a regular diploma, but the only thing that was holding me back was passing my language TCAP test. I was involved in many clubs and extracurricular activities, such as Drama, Color Guard, and the Dance line team, but I often had to sacrifice participating so I could attend tutoring after school. In some ways I was sad because I really wanted to do Drama, but I knew that my education came first. With all the tutoring and prayers from many people, my dream came true. I passed my TCAP test with a 94.

May 24th was the biggest day of my life. It was the day that I graduated from high school. As I sat through graduation, there was one more thing that I really wanted. It was to win the Student-Teacher Achievement and



Breka Moore



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# Explorers Unlimited—A Reality for Campers with Down Syndrome

By Heather Gillum

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**E**xplorers Unlimited! While it sounds like the latest version of reality television, Explorers Unlimited *became* a reality this year through the joint efforts of the John F. Kennedy Center for Research on Human Development and the Down Syndrome Association of Middle Tennessee. Explorers Unlimited was a month-long day camp for individuals with Down syndrome between the ages of 12 and 22 years, held at University School of Nashville. In its inaugural year, Explorers Unlimited enrolled 12 campers who sang, danced, signed, and painted



Chrissy (left) and Christina celebrate the success of their Campfire Program.

their way to individualized expression and academic achievement throughout camp.

The primary goal of Explorers Unlimited, as established by Camp Director Susan Eaton and Academic Director Kathy Karns, is to provide

an opportunity for self-expression and self-directed learning experiences for the campers. Too often the choices facing individuals with Down syndrome are made for them: choices like what academic and career paths to pursue, where to live, and with whom to share their lives. Explorers Unlimited sought to give campers the “unlimited” opportunity to make choices over the course of camp, leaving the counselors with the responsibility of making it happen in an academically enriching way.

Christina Mockridge served as one of three small group leaders during camp. Over the first two weeks of camp, she realized that her group was unanimously enthusiastic about dinosaurs, as evidenced by the books they selected at the Metro Nashville Public Library. In preparation for the weekly Campfire Program, a multimedia camper-led program presented each Friday afternoon, Christina assisted her group with painting clay dinosaurs and making an “exploding” volcano that spewed vinegar and baking soda (providing lessons in both geology and chemistry). The group wowed the crowd with a conga line performance to Jimmy Buffett’s “Volcano Song” and presented their creations to an appreciative audience of staff and family members. Other highlights of the weekly Campfire Program were a heartfelt rendition

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Recognition Award (S.T.A.R.) To apply, I had to write about a teacher who had influenced me. I wrote about my special education teacher because she was always there to support me through the years. Hoping and believing in myself, I won the award. I am happy to say that I graduated from Milan High School with the class of 2002 with an honors diploma.

Now I am attending Dyersburg State Community College and majoring in Early Childhood Education. I hope in the future that I will have the opportunity to speak to people and students about children with special needs.

I would like to thank the Tennessee Council on Developmental Disabilities, my family, friends, and the faculty and staff of the Milan Special School District for giving me the opportunity to reach my dreams and goals. ■



of Louis Armstrong's "What a Wonderful World" presented in sign language, and the presentation of original autobiographical books containing writings and photographs from the campers.

Unlike other camps and conferences that bring together participants from across the country, Explorers Unlimited is truly a local camp, enrolling campers from Davidson, Robertson, and Williamson counties this year. This regional focus allowed campers to form lasting relationships that are more likely to be sustained after camp through local visits and informal reunions. Camp also emphasized independent living skills needed to explore the Nashville area, including rides on city buses and trips to local grocery stores to purchase food for weekly potluck lunches. Other off-campus trips took campers to a neighborhood pharmacy, Ben and Jerry's Ice Cream, Target, and out to eat. Each of these experiences served to reinforce skills being addressed in the on-campus academic sessions of camp, which addressed literacy, math (with a focus on money skills), and social skills (including personal safety and social appropriateness).

Another highlight of camp was the involvement of the Frist Center for the Visual Arts. A center representative made regular visits to camp, leading campers in a variety of artistic endeavors. During the final week of camp, camper creations were installed in the Frist Center where campers and staff enjoyed them during a private reception.

But camp didn't benefit the campers alone. Camp staff had the opportunity to interact with a group of individuals with Down syndrome in a unique environment, one in which individual strengths of campers were showcased, challeng-



This year's Explorers Unlimited campers.

ing preconceived notions and stereotypes. As I interacted with campers during a daily reading session, I was consistently reminded of their strengths, encouraging me to "raise the bar" of my expectations, and to provide additional support only when truly needed. Group leaders noted that following the campers' interests gave them the opportunity to discover what was meaningful to each camper, and, in turn, to develop motivating incentives to encourage completion of rigorous academic assignments. All staff associated with the camp agreed that this experience shed new light on Down syndrome and will influence their practices in the future. ■

For more information on Explorers Unlimited or the Down Syndrome Association of Middle Tennessee, contact Sheila Moore, Executive Director of DSAMT, at (615) 386-9002.

**Heather Gillum, a speech-language pathologist, is currently pursuing a Ph.D. in child language through the Department of Hearing and Speech Sciences at Vanderbilt University.**

# TRIAD Summer Camp Pairs Children with Autism with Typical Peers

By Ned Andrew Solomon

**A**ndy Sommers learned quickly at summer camp that if he followed the rules, and earned enough marbles, the payoff was worth the effort: an ice cream or pizza party, a special treat or privilege. And the way to earn a marble was basically just doing the right thing. "I have to stay in my seat, raise my hand, answer questions, be quiet and listen to others," says Andy, listing acquired social skills that any parent would be proud of, but especially challenging for a child with autism.

Andy is one of 40 kids who attended the TRIAD (Treatment and Research Institute for Autism Spectrum Disorders) Social Skills Summer Camp for children with autism and typical peers, a component of the Child Development Center at Vanderbilt University Medical Center. Autism is a neurobiological condition that has a significant impact on how a child communicates, interacts with others, and in

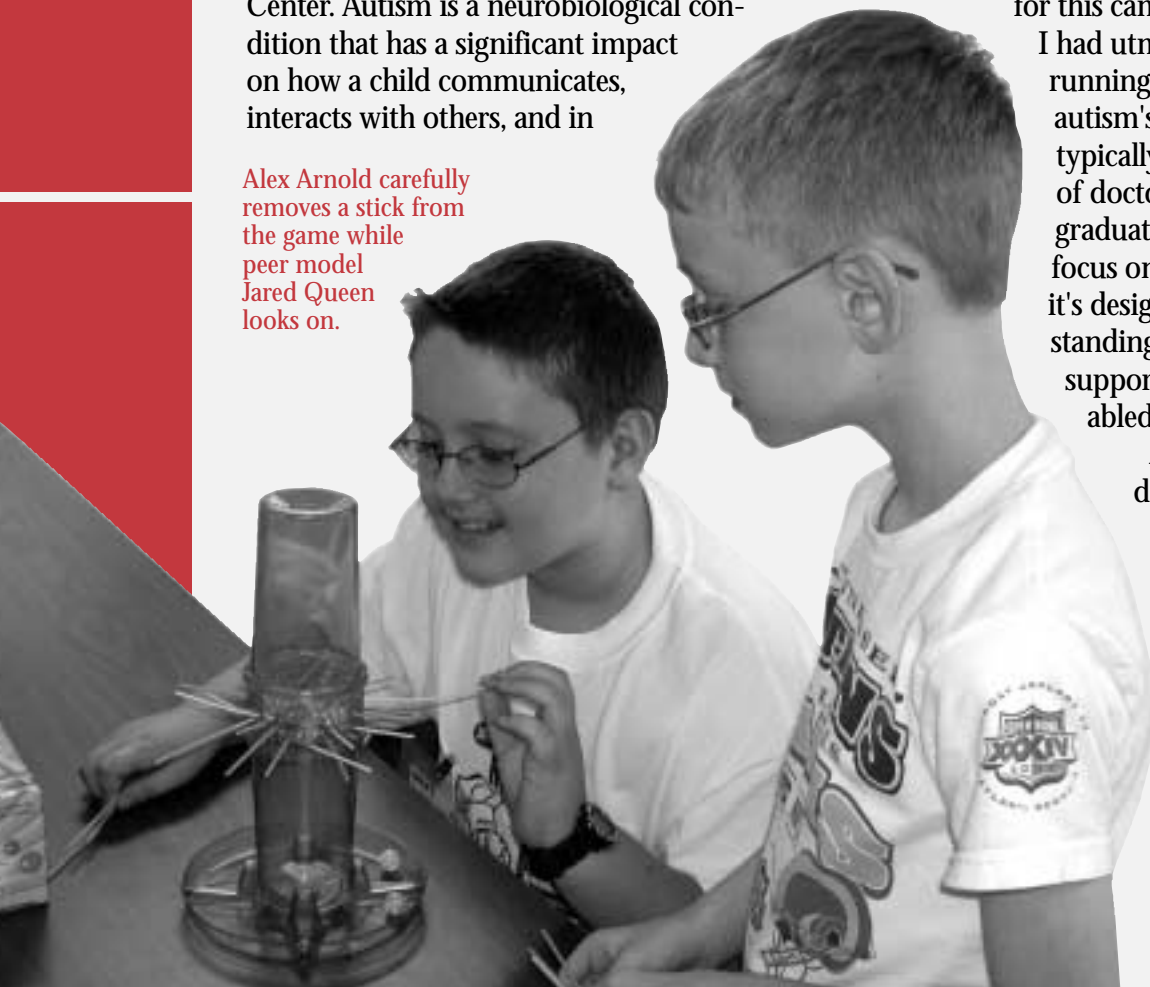
Alex Arnold carefully removes a stick from the game while peer model Jared Queen looks on.

general, perceives the world. Although there has been a great deal of research on autism in recent years, there is currently no known cause or cure. Based on data from the 2000 U.S. Census and the prevalence of autism (one of every 600 children), it is estimated that there are at least 3,000 children age 0-21 with autism in Tennessee.

Although there is a great need in the community for summer programs for children with autism, the TRIAD camp is currently the only one that specializes in this area. Leisa Hammett-Goad, whose daughter Grace was one of this year's campers, certainly appreciates the value of this program. "Our family has been very fortunate to be able to participate in several good camps for typically developing children, some with built-in modifications for Grace, such as an assistant. However, I have the greatest enthusiasm

for this camp because from the beginning I had utmost confidence in the people running it. It's a parent of a child with autism's dream—nearly one-to-one typically developing peers, and a staff of doctoral students, master's level graduates and others—all with a career focus on autism. It's structured, and it's designed with a concrete understanding of the learning challenges, supports, and needs of our uniquely-abled children."

As many researchers have discovered, some of the most potent teachers are same-age peers, so this unique three-week summer experience combines kids with autism with typically developing peers in a fun and educational, activity-based program that promotes good social interactions, and





winds up being beneficial to all the children.

The peers soon learn that they have far more in common with their new friends with autism than differences. “The peers are very open to the kids with autism,” says camp director Misty Ballew. “I think it’s because they can see in many ways they’re pretty typical. They can play games, soccer, basketball—things that the peers enjoy doing themselves.”

Although the most apparent manifestation of autism is a lack of appropriate social interactions, kids with autism have a wide range of abilities, and some excel in certain areas way beyond their typical peers. “With autism we have all different levels, cognitively, emotionally, socially,” explains Ms. Ballew. “We have some kids at camp whose IQ’s are probably over 140. They can tell you definitions of anything, and use words that I have to look up, but socially they might be at a 5- or 6-year-old level.”

The camp recruits kids in the 6-11 age range, and groups are broken up by ages: below 9 years, 9 and 10 years, and this summer, a large group of 11-year-olds. The day is divided between free play, small and large group times, and meals, which are also treated as teaching opportunities for positive social interactions. The camp is currently located at the Belle Meade United Methodist Church. There is a cost to attend, but fees are reasonable because of financial support from the Vanderbilt Community Giving Campaign, the Medical Center Staff Advisory Council, and scholarships, thanks to contributions from Sylvia Zisman, a private donor.

Each of the camp activities is based on a particular daily theme. It’s Andy Sommers’ second year at TRIAD camp, and he has become



Peer model Norma Courey and Andy Sommers participate in a role play together as Andy reads from his script.

quite a good reporter of what goes on here. “We did slime,” says Andy, “we ordered ice cream, we talked about greetings, warm and cold messages, and good sports and bad sports.” Other social skills include making introductions, inviting others to play, joining a group, compliments (or in Andy’s better words, warm and cold messages), emotions, and all the mechanics of making conversation: starting one,

choosing and maintaining a topic, and ending one appropriately.

Fun activities are cleverly geared toward putting a particular skill into practice. One day an ice cream vendor came with his truck, and all the campers had to place their own frozen treat orders. Though all the kids had practiced this exercise several times in groups, the actual act was extremely challenging. “A lot of it’s related to the anxiety of a different situation,” says Ms. Ballew. “They’re thinking, ‘Am I going to say it right? Is he going to understand me? What if he doesn’t—and then not knowing how to repair it.’ There is so much that goes into it!”

Although there is currently no formal research going on here to determine how much skill retention occurs or generalization to other settings, director Ballew hopes that at some point during future camps they can explore those issues. “Because autism is a life-long disability,” says Ms. Ballew, “there are always going to be things that the children, and adults, will need to work on, especially in certain social situations. But we saw children return from last year who remembered what they were taught and were ready to move on to the next skill.”

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While the kids are busy building their skills, the staff is learning too. Most are graduate students in psychology. Many have only read about autism, while others have had clinical experiences. Counselors get a day-long training before camp begins that covers the basics of autism, strategies for working with the kids, and creating lesson plans. Training continues throughout the three weeks, as spontaneous situations arise that lead to discussions or problem solving.

Farrah Jacquez is getting her Ph.D. in clinical psychology from Vanderbilt. The camp originally appealed to her because it was a way to get required clinical hours in. "This is a great and fun way to get it," says Ms. Jacquez, "because you spend all day with really great kids, and play all day!" However, it may wind up being one of the most memorable summer breaks she has ever had. "The most rewarding thing is seeing how much the kids love it," says Ms. Jacquez. "To plan activities and see them laugh and have a great time, and seeing them go away at the end of the day having learned a particular skill.

In the morning they couldn't do it, and in the evening it seems like they can, or someone will come up and do something that we learned at the very beginning of the week. I feel like it's in there somewhere—and they have it, it's just when they choose to pull it out."

The typical peers, or peer models as they're called, have a short pre-training, too, an orientation that includes an explanation of what autism is, and a frank discussion of individual strengths and weaknesses of autistic kids, and of themselves. "We explain that kids with autism might be really good at reading or drawing," says Ms. Ballew, "but what



Junior Counselor, Luke Mirtes, explains something to another child.

they're generally not good at is talking to their friends, or playing games. That's why the peers are here, to help them do these things more appropriately."

Throughout the three weeks, brief peer follow-ups are conducted to address questions and concerns. "I think it helps that the peers are incorporated into the entire day," continues Ms. Ballew. "There's not a time when we're just working with the kids with autism. So the peers are getting

the social skills lessons, too. For instance, talking about being a good sport. That's something all kids struggle with at 8, 9, 10 years old."

Ms. Hammett-Goad believes strongly in the benefits of using peers to foster appropriate social skills. "For my child and our family, incorporating typically developing peers is a necessary criterion for a camp," she says. "My daughter is fully included in school and it would be regressive to do otherwise at camp. Such peers model typical behavior. It is through them, by them, and with them that she learns to meld more into a society that expects 'neuro-typical' behavior of its members. Furthermore, perhaps I am biased in saying this, but I believe with conviction that learning and playing alongside children like Grace is a gift not just to her but to the other children."

One of the primary goals of the program is to send these typical kids, who have learned to accept children with autism, into their local school systems where they will encounter other students with autism, and transfer their sensitivity and experiences to other peers in the classroom, and even teachers.

Based on the success of the first two years, it is almost a guarantee that the camp will continue to be a summertime option for children with autism and their families, typical peers who are looking for a way to have fun while helping others, and college students who are seeking educational experiences beyond the classroom and the textbook. ■

# Scholastic Success Given Boost on State Campuses

**T**he campuses of our state's colleges and universities are among the communities opening to people with disabilities. There, as elsewhere, these individuals may need certain aids or supports to succeed. In this article, three college administrators look at how their institutions assist students with disabilities. ■

## By John Harris

A number of universities in Tennessee have committed themselves to making programs and activities available to students with disabilities. Some have designated an office and hired full-time staff to serve individuals with disabilities. As a long-time service provider—nearly 16 years—I am excited to see the number of schools, both public and private, that have directors or coordinators of disability services.

A major role of service providers is assisting students to find funding for their education. Forty to fifty percent of Tennessee students with disabilities, particularly at public institutions,

receive their aid through the State's Division of Vocational Rehabilitation. Vocational Rehabilitation funds pay for tuition,

books, supplies, academic aides, personal care assistance, and, in some cases, the purchase of equipment.

Fourteen Tennessee universities have contracts with Vocational Rehabilitation to help meet the needs of students with disabilities.

The staff of disability services offices also assist students in completing financial aid forms and applying for scholarships. Sources include the American Council for the Blind, the National Federation for the Blind, Nike Scholarships, the Minnie Pearl Scholarship for students with significant bilateral hearing difficulties, and the Marion Huber Learning Through Listening Award.

You can learn more about available scholarships on the Grantseeker website at [www.regis.edu/grants/scholar6.htm](http://www.regis.edu/grants/scholar6.htm). This is just the tip of the iceberg! Much more funding is available to enable students with disabilities to attend college.

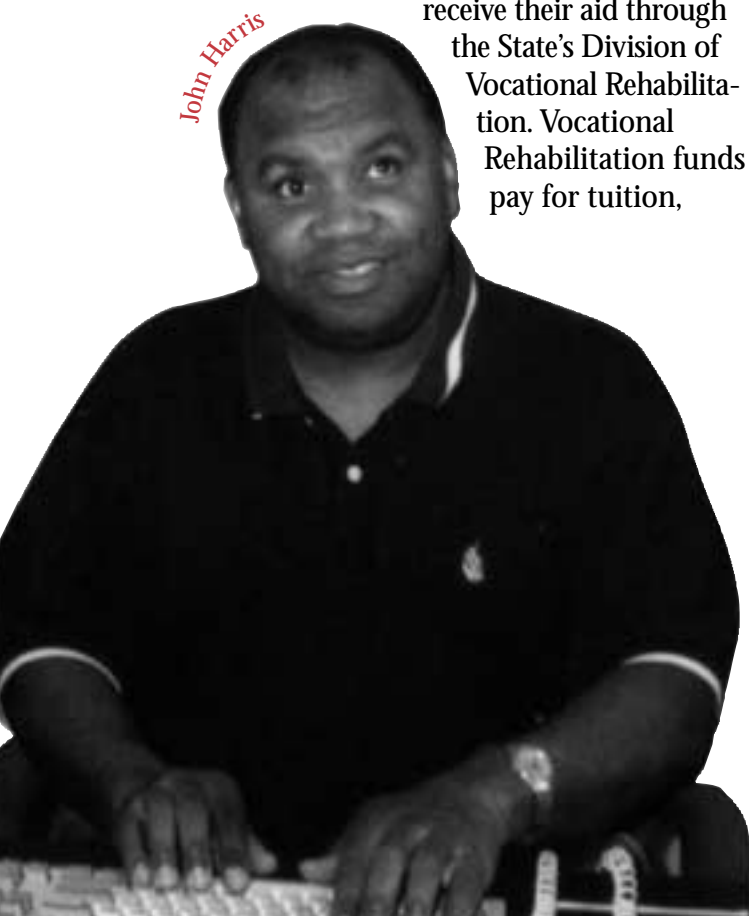
*John Harris is Director of Disabled Student Services at Middle Tennessee State University in Murfreesboro. ■*

## By Sara Ezell

The Disability Services staff at Vanderbilt University ensure equal access to the University's programs and activities to all students, regardless of disability. We offer many services to those students who have a documented disability. We serve students with a variety of disabilities.

The largest population of students that we serve have a learning disability. When a student notifies the Opportunity Development Center that he or she has not been diagnosed with a learning disability in the past, but is feeling extremely frustrated with class work, taking notes, or understanding reading assignments, the student will be referred for diagnostic testing. If a student already has been diagnosed with a learning disability, a copy of the most

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These students take advantage of  
MTSU's special services.  
(Right) Cory Poder  
(Below left) Herbert Lee Phillips  
(Below right) Sindy Greenwell

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recent documentation is forwarded to the Disability Services office to identify services to be provided.

An intake interview is arranged between a member of the Disability Services staff and the student (whether newly diagnosed or diagnosed previously) to outline the services available and procedures for receiving accommodations. Typical accommodations include time plus half on tests and quizzes, textbooks on audiotape, notetakers, and referrals for tutoring and study skill counseling at the Learning Center.

We also coordinate services for students with other disabilities. The ODC can arrange for sign language interpreters and notetakers for students who are deaf or hard-of-hearing students. Students with visual impairments can receive materials in alternate formats (e.g., Braille, tape recorded, enlarged, etc.), notetakers, access to screen reading software at libraries, and access to orientation and mobility training for navigating

the campus. Students with mobility impairments can receive preferred housing assignments, handicapped parking passes, and a campus map outlining accessible entrances and pathways on campus.

All of these services are individualized, so this is by no means an exhaustive list. Reasonable accommodations are tailored to meet the needs of the students per their documented disabilities. Students are required to sign a contract that outlines their responsibilities, such as notifying the ODC office of upcoming tests in a timely manner, alerting the ODC of any problems as they arise, and the honor code requirements for taking tests in an alternate environment. After the initial interview and orientation, students are simply required to follow these responsibilities and remain as anonymous as they choose regarding receiving services.



The foundation of the services at Vanderbilt University is having open communication between the student and the Disability Services staff so that everyone can be a successful member of the Vanderbilt community. Speaking as a Vandy alum with a disability, this campus is a great place to get a quality education and enjoy a memorable college experience!

*Sara Ezell is assistant director for disability services at Vanderbilt University and serves as chair of the Tennessee Council on Developmental Disabilities.* ■



Sara Ezell

#### By Alan Muir

The goal of the Office of Disability Services at the University of

Tennessee is to ensure equal access to University programs and activities to all students, regardless of disability. Nearly 70% of the students with disabilities registered with the Office are those whose disabilities are hidden, including learning disabilities, attention deficit hyperactive disorder, chronic health issues, and behavioral health disabilities.

The process of accommodation, to ensure equal access, begins with the submission of recent documentation of the student's disability. In the area of learning disabilities, the Office requires documentation no older than three years. If a student has not been previously diagnosed with an LD and is academically struggling, the Office will refer the student to a number of local professionals in the area or on campus to undergo testing. Reevaluations may be necessary during a student's career at UT due to changes in the student's performance or the lapse of a period of three years. Accommodation plans are individualized to the needs of the student, including followup appointments. Plans are modified to reflect the progress and performance of the student. The accommodations, mutually decided upon between the staff and the student, are communicated via memo to the student's professors in

those classes where the student feels accommodations are warranted.

Many of the accommodations offered by our Office are much the same as most disability services offices on other campuses, including note taking and reading services, sign language interpreters, books on tape, extended time for exams, and distraction-less exam environments. UT also



Alan Muir

offers accessible van transportation through Parking Services as an adjunct service of Disability Services.

One area that UT's Office of Disability Services is developing over the next year or two is an increased usage of technology to supplement notetakers, readers, and other types of

accommodations that required staff or volunteers to accomplish. This shift in emphasis provides greater flexibility to the student, since technology is available when the student needs it. Among the technological aids already being used are screen-reading software, dictation software, an improved website, and an e-mail distribution list to communicate with students. These technological advances will enable students to achieve greater independence and assume more of the responsibility for their own performance. Training in the use of these devices is offered through the Assistive Technology Lab, as well as followup to see that the technology is a "good fit" for the student. There is a keen awareness in the Office that the University is a step in the process for a person with a disability to a life of independence and productivity.

To further prepare students for life beyond graduation, there is a career component offered to students. The Disability Careers Office (DCO) is a joint effort between Career Services and the Office of Disability Services. The DCO provides one-on-one assistance to students with disabilities.

*Alan Muir is former director of UT's Office of Disability Services and is a member of the Tennessee Council on Developmental Disabilities.* ■

# When It Comes to Insurance Benefits, Know Your Rights

By Andrea L. Cooper

I am writing with the hope that those of you with significant disabilities, private insurance through an employer, and a need for covered medical services will learn from my experience with a pain in the neck. I mean that literally.

I have had a C3-level spinal cord injury for over five years, and I have learned to manage the pain that constantly accompanies my contracted muscles. However, over a weekend not long ago, I developed excruciating neck pain that radiated into my jaw, ear, shoulder and head. My usual tricks with heat, stretching, medication and massage failed, so I called my neurologist. Recognizing that I do not cry wolf, he scheduled me for an appointment the same week and instructed his nurse to set up a physical therapy evaluation.

Those of you familiar with Murphy's Law will not be surprised that this pain in the neck coincided with two of the three seminars that I must attend annually to keep my law license active. Having heard nothing from a physical therapy company, I proceeded to the seminar. During a break, I retrieved my telephone messages. One message was from a home care company confirming that they had received the referral from my doctor. The next message was from the company's physical therapist wanting to stop by my home in 30 minutes to do my evaluation. The next message was from an administrator at the home health company

announcing that my insurance company had approved the evaluation. The final message was

from the same physical therapist. "Ummm... I'm trying to reach an Andrea Cooper, ummm ... I'm trying to schedule a physical therapy evaluation ..."

These messages were left within a two-hour time period. I immediately returned the therapist's call to find that she had even called my mother in Indiana to track me down! Unsure what to make of her persistence, I explained that today would not work because I was in the middle of the seminar.

## **Treatment declined.**

"A what? What do you mean by that?" she interrogated. I did not have the

time to brief her on my profes-

sion or the Tennessee Supreme Court requirements for maintaining my law license (nor was I sure why it was her business), so I elaborated with, "an educational seminar." At that point, she concluded that if I was at a seminar, I was not "homebound," and she could not treat me. I reminded her that I had private insurance and that this was not a Medicare claim subject to federal homebound regulations. Still, she insisted on following up with her office.

I returned home to receive a message that the physical therapist left with my husband. The therapist called my insurance company, announced that I was not "homebound," and asked if the insurance company would still cover my evaluation. She told my husband that the insurance company then refused to cover



Andrea Cooper



# Cost of Statewide Disability Directories Reduced

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The 2001-2002 *Disability Services and Supports Directory* is a publication of the Tennessee Disability Information & Referral Office. The statewide directory of community agencies and disability resources is available

in three volumes, East, Middle and West Regions. Cost per directory has been reduced from \$40.00 to \$20.00 for each directory, plus postage and handling. The statewide set of three volumes has been reduced from \$80.00 to \$40.00. To purchase a directory or for additional information, call our office at 800-640-INFO (4636) or

complete an order form online at: [kc.vanderbilt.edu/devents/order.html](http://kc.vanderbilt.edu/devents/order.html)

*The Tennessee Disability Information and Referral Office is a project of the Tennessee Council on Developmental Disabilities located at the John F. Kennedy Center for Research on Human Development at Vanderbilt University.*

the evaluation, so as a "courtesy" she would notify my doctor that her company could not treat me. Based on two phone calls, a physical therapist summarily denied my physical therapy benefit to which I am entitled under my insurance plan.

I'll bet these self-proclaimed "insurance experts" do this to insured individuals all the time, simply because they do not know their coverage or their rights. I have a copy of my entire employer-sponsored insurance plan; not just the "summary" that the human resource department hands employees at the beginning of each year. There is no definition of "homebound" in the plan document, let alone any requirement that recipients of medical services in the home be "homebound." There is, however, a provision (as required under a federal law known as ERISA) that any denial of benefits be conveyed to me in writing specifically explaining the facts and the provisions of the plan document on which the denial is based and outlining my right to appeal and exactly how to appeal. Moreover, I must be told how I can obtain a complete plan document in the event that I do not already have it.

**Getting the facts.** Knowledge is power, and it does not take any more knowledge than what I have just outlined to know that the therapist

and whomever she claimed to speak with set up the insurance company and, unfortunately, my employer for a slam-dunk lawsuit. I speak from experience. I had another denial of benefits executed in the same slipshod manner by similarly unqualified people. I sued; I got my benefits; and I got reimbursed for the expenses that I incurred in the meantime.

If you have private insurance through an employer-sponsored plan, be sure that you write to the plan administrator and request a complete copy of the plan document. This is not the same as a Summary Plan Description. If you do not have the address for the plan administrator, ask your human resources department for it. You cannot know your rights if you do not have a complete copy of your health insurance plan. If you do not know your rights, you are at risk of having unqualified individuals such as home health workers make legal determinations for you. If you still have difficulty getting benefits to which you feel you are entitled under your plan, see an attorney. A denial of benefits can be a lot more than a pain in the neck. ■

*Andrea L. Cooper is a member of the Tennessee Council on Developmental Disabilities and contributes regularly to Breaking Ground.*

# The Tennessee Family-to-Family Health Information Center

By Dara Howe

Tennessee is one of six states recently awarded federal grant funds to operate family-directed health care education and information centers to address the needs of children with chronic illnesses or disabilities.

Family Voices of Tennessee at the Tennessee Disability Coalition is the lead agency for the Tennessee Family-to-Family Health Information Center, a four-year project funded by the U.S. Health Resources and Services Administration's Maternal and Child Health Bureau. The grant supports a family-directed initiative to increase the knowledge, ability, and satisfaction of families so they can participate and advocate effectively on behalf of their children's health care needs.

The Tennessee Family-to-Family Health Information Center or "F2FHIC" is a partnership with the State of Tennessee, Vanderbilt University, Tennessee Voices for Children, and others.

Major goals for the center include: 1) the development of data systems to identify needs and guide development of strategies that will help families meet their children's health-related needs; 2) dissemination of current, accurate and linguistically appropriate information to families about available health care and related services or resources; 3) the provision of training opportunities for families and providers; and 4) support for family/professional collaboration at all levels with a special emphasis to increase the participation of families of children

with special health care needs on policy committees and forums affecting children.

The center is staffed by three family resource specialists who are experienced parents or family members of children with special health care

needs. There is one family resource specialist residing in each of the state's three grand divisions: East, West, and Middle Tennessee, with responsibility for serving families in their respective regions.

Parent-to-parent or family-to-family support and interaction has proven to be an effective mode for helping families learn, cope, and respond appropriately to the needs and challenges of their special needs children. It's a complicated world of services out there. Most of us need a little or a lot of help to figure it out and know what to do to access all the services available to our children.

Family Voices of Tennessee and its host

organization, the Tennessee Disability Coalition, are well prepared to operate the F2FHIC center grant. They were among the handful of programs who participated in a pilot project funded through the national Family Voices organization.

We are indeed fortunate to be on the front edge of this movement. There is legislation in Congress called the Family Opportunity Act that, when passed, will fund these family-directed health information centers in every state. That is secondary to the bill's main purpose, which



Dara Howe and son Alex



is to allow families that include kids with disabilities to buy into benefits available to children on Medicaid.

The dramatic changes to TennCare gave a strong impetus to our grant application. We are going to be very busy helping families sort out TennCare eligibility and coverage issues for quite some time. Of course, we're also helping families with other insurance issues, and providing training and information about the range of federal and state programs that help kids and families.

Working closely with F2FHIC is Dr. Melanie Lutenbacher, director of the Pediatric Nurse Practitioner program at Vanderbilt's School of Nursing. Dr.

Lutenbacher, who also parents a son with a disability, is consulting on the development of data systems, including family surveys, as well as overall program evaluation. Focus groups of families are being convened this fall as a first step to gathering information about the needs of Tennessee's families with children who have chronic illnesses or disabilities.

Another key partner in the Tennessee F2FHIC is Tennessee Voices for Children (TVC). We greatly value and need TVC's expertise on children's mental, emotional, and behavioral health issues. Connie Nelson will be leading the TVC efforts to develop training modules on these issues.

The other core partner in the F2FHIC grant program is the State Department of Health and its Children's Special Services (CSS) program.

CSS will help us reach out to the families they serve. Their Parents Encouraging Parents (PEP) program, which connects new parents to other parents of children with similar diagnoses, is an important referral source for us.

Parent-to-parent or family-to-family support and interaction has proven to be an effective mode for helping families learn, cope, and respond appropriately to the needs and challenges of their special needs children.

Two things about the Tennessee Family-to-Family Health Information Center serve as focal points for activity. The first is a commitment to reach out to help under-served, under-represented communities and populations in Tennessee. The second is a commitment to operate "family-

centered care" for families. This means working with health providers, including clinics, hospitals, and professional groups, to promote the benefits of partnering with families as the optimal means to high quality care and best outcomes for children with complex needs.

For example, we would like to see every pediatric clinic, hospital, or provider group establish a family

advisory committee. That would be a good start. Ideally, every practitioner or provider who serves children would be oriented and trained to relate to families as partners.

Families need training too, of course. It takes knowledge, skill, and confidence to relate on an equal basis with your child's doctor.

These are worthy but ambitious goals. Our approach is one family, one practitioner at a time.

To contact or learn more about Family Voices of Tennessee and the Tennessee Family-to-Family Health Information Center, visit the website:

[www.tndisability.org/familyvoices](http://www.tndisability.org/familyvoices)

or, send email to:

[familyvoices@tndisability.org](mailto:familyvoices@tndisability.org)

or call toll-free: 1-888-643-7811

(Nashville area, call:

(615) 383-9442). ■

***Dara Howe is  
director of Family  
Voices of Tennessee  
and the Tennessee  
Family-to-Family  
Health Information  
Center.***

# Some Find Small Business a Road to Independence

By Jim Summerville

*Ed. note: This is the second of two articles about microenterprises and people with disabilities. The first part appeared in Breaking Ground Issue No. 7, August 2002.*

**A**lthough she had once traveled around the world working as a teacher, Laverne Lowery was told that she'd never do anything again after a spinal cord injury.

That was five years ago. Today Ms. Lowery operates her own business, L&L Cosmetology Enterprise. The small company, run from Ms. Lowery's Memphis home, provides both beauty care services and tutoring in the field.

L&L Cosmetology is part of a growing field of microenterprises. A microenterprise is typically a business with five or fewer employees that

requires startup capital of no more than \$35,000.

Most microenterprises create employment for their owners and, in some cases, family members. They can be formally organized as a sole proprietorship, a partnership, a family business, or a corporation.

Like many others who start and manage these small businesses, Ms.

Lowery initially received help from a microenterprise development program. She turned

to the Opportunity Banc at the Metropolitan Inter-Faith Association (MIFA) of Memphis. The Opportunity Banc provides training and small loans to entrepreneurs.

**Disability no barrier.** Ms. Lowery received training in business methods at the Opportunity Banc. She learned about planning, marketing, and money management. "When I passed my

classes, that gave me the incentive to get started," Ms. Lowery says. "I'm always networking," she says, and adds, "I don't let my legs keep my hands from working."

Another microenterprise success story from the Bluff City began at the Memphis Center for Independent Living (MCIL). In early 1997, Ms. Deborah Sanders was volunteering there, when she heard about a new MCIL project, the GOALS program. GOALS stands for "Gainful Opportunity Advocacy Leadership Society." Its purpose was to lend money, train, and provide ongoing technical assistance to microenterprises.

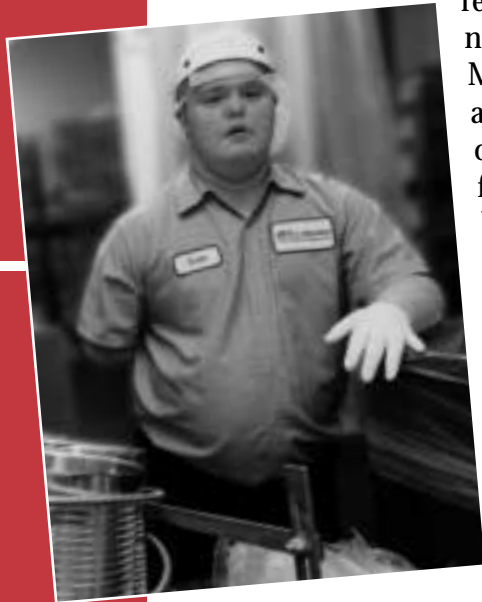
Ms. Sanders, who has cerebral palsy, joined with about two dozen entrepreneurs, taking classes sponsored by GOALS and, in time, taking out a business license to manufacture and sell ceramic pieces, doing business as "Agape Icons by Deborah." Her success has enabled her to repay three loans from GOALS that helped get her business going.

"I enjoy my work 100%," Ms. Sanders says. "I can set my own pace and go about my day the way I want to."

"Agape Icons by Deborah" is typical of microenterprises in that they often grow out of the owner's interests and abilities. Common types of microenterprises are repair services, cleaning services, arts and crafts, clothing, computer technology, child care, and environmental products.

**An independent living.** According to Michele Flynn, executive director of the Tennessee Network for Community Economic Development, about 25% of people managing a microenterprise in the Volunteer State have a disability. "Individuals with a disability like the freedom, flexibility, and independence of working for themselves," she observes.

These needs and desires for independent ways of earning a living are recognized at Arc-Diversified, a microenterprise development program affiliated with the Advocacy and Resources





Opposite page and above:  
Workers from Arc Diversified. Seventy  
percent of its employees have a disability.

Corporation, a local chapter of The Arc of Tennessee. Arc-Diversified, located in Cookeville, is a manufacturing facility that provides training and employment to individuals, 70% of whom have some type of disability, ranging from vision impairments to Down syndrome.

One of the product lines made at Arc-Diversified is Granny Bunt's "Complete Bakery Mixes." Oma Lee Durm was born and raised in the foothills of Tennessee. Called "Bunny" by her father, "Bunt" became the name used by family and friends as she grew older. After World War II, she married Orval Durm, called "Bull" by his many friends, and Bull and Bunt raised five children on their farm. The family table was often laden with Southern style food.

Granny Bunt loaned her personage and her reputation for fine cooking to Arc-Diversified, and her product lines now give employment to 160 people. Some 20-40 truckloads of food products, traveling to 40 different states, leave Granny Bunt's warehouse each week. The biggest seller is Vitamin A fortified vegetable oil, purchased in quantity by the U.S. Department of Agriculture for humanitarian relief around the world.

**Calling the shots.** Like Arc-Diversified, Mike and Fran Moyers, of Sneedville, saw an opportunity to build a business around a line of specialty foods. Both the Moyers were drawn to microentrepreneurship as a way of making a living while managing their chronic disabilities.

The Moyers originally heard about others involved in small businesses through the Jubilee Project, Inc., a program of the United Methodist Church. Jubilee Project helps people with disabilities and others to find work that matches their abilities. Jubilee Project's Cooperative ("The Co-op"), with assistance from the international philanthropic Heifer Project, helped Mike Moyers get started with honeybee hives, in exchange for a percentage of the hives' production to support the work of the co-op.

Two other co-op partners then lent a hand. The Clinch-Powell Community Kitchen, a Jubilee-owned facility, provided facilities for processing the hives' production, and the Appalachian Springs Cooperative, a member-owned association of family farmers and small food manufacturers, helped with getting the Moyers' honey to commercial markets.

Ms. Lowery, Ms. Sanders, Mrs. Lee, and the Moyers are all part of a fast-growing socioeconomic movement. According to the Association for Enterprise Opportunity (AEO), "small amounts of capital, when combined with training . . . can improve employment opportunities . . . and incomes" for people with disabilities. ■

*Jim Summerville*  
is editor of  
*Breaking Ground.*

# Partners Celebrates Tenth Anniversary of Training Community Leaders

*By Ned Andrew Solomon*

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**O**n September 13, 2002, 27 adults with disabilities and parents of children with disabilities from across the State gathered at the Doubletree Hotel in downtown Nashville to kick off the tenth year of Partners in Policymaking.

Partners in Policymaking Leadership Institute™ is a training initiative of the Tennessee Council on Developmental Disabilities.

Participants are provided with the knowledge and experience to make changes in the policies that have an impact on themselves and their families, and the invaluable opportunity to network with other family members, adults with disabilities, local and national leaders in the field of disabilities, and policymakers. They gain confidence in public speaking, meet with legislators, and, most importantly, learn to stand up for their rights and for the rights of others.

The curriculum includes:

- History of Perceptions of and Services for People with Disabilities
- History of the Parent, Self-Advocacy, and Independent Living Movements
- Inclusive Education
- Strategies for Community Inclusion
- Service Coordination
- Futures Planning
- Self-Determination

- Assistive Technology
- Supported, Competitive Employment
- Supported Living and Home of Your Own
- Strategies for System Change (Including How to Work with the Media, How to Conduct Effective Meetings, State and Federal Legislative Processes, and How to Prepare and Present Testimony)

Partners graduates become actively involved with community and advocacy organizations, serve on boards and committees, and challenge political candidates to respect and to protect the rights of Tennessee's citizens with disabilities.

The 2002-03 class already has a great head start in the leadership department. Their impressive list of associations include:

- The Arc of Tennessee and its local chapters
- ADAPT
- Autism Society
- Centers for Independent Living
- Council for Exceptional Children
- DCE-Disability Coalition on Education
- Down Syndrome Association
- Easter Seals Parent Support Group
- LDA-Learning Disabilities Association
- Ms. Wheelchair Tennessee
- NARHA-North American Riding for the Handicapped







Opposite page and above:  
Partners and Council staff throughout the years.

- National Multiple Sclerosis Society
- PALS–Partners Accessing Life
- Project DOCC–Delivery of Chronic Care
- Project LINK–Leaders in Education Networking for Kids
- SPAN–TN–Special Education Action Network of Tennessee
- STEP–Support and Training for Exceptional Parents
- TIPS–Tennessee Infant Parent Service
- ...and many, many others.

For those of you unfamiliar with Partners, each year, a class of 25-30 participants is selected from across the State. To recruit the class, the Council disseminates flyers and applications throughout the State. An effort is made to utilize the word-of-mouth network of all Partners graduates since 1993, traditionally our greatest source of referrals.

During the final selection process, a team of individuals, including the director of Partners, the Executive Director of the Tennessee Council on Developmental Disabilities, and representatives from the Executive Committee of the Council, review applications. The goal is a class with diversity in the following areas: adults with a disability or a family member of a person with a disability, geographic location (especially equal representation from East, Middle and West Tennessee), ethnicity, age, gender, and type of disability.

Here's the roster of the 2002-03 Partners in Policymaking class:

Catherine Bailey, *Chattanooga*  
Cheryl Coleman, *Crossville*  
Laura Corby, *Cordova*  
Joanne Cunningham, *Cordova*

Sarah Davis, *Oak Ridge*  
Darrin Decker, *Murfreesboro*  
Kathleen Donaldson, *Smyrna*  
Jerome Franklin, *Nashville*  
Keith Greenwald, *Memphis*  
Kathryn Huffman, *Collierville*  
Anthony Harrison, *Columbia*  
Beverly Carol Hart, *Cordova*  
Pamela Huber, *Kingsport*  
Molly King, *Antioch*  
Sandi Klink, *Memphis*  
Donna McGaha, *Sevierville*  
Iva McGavock, *Nashville*  
Patricia Nunally, *Memphis*  
Katherine Peatross, *Memphis*  
Pam Rader, *La Vergne*  
John Shouse, *Franklin*  
R. Thor Spencer, *Louisville*  
Bobby Sumpter, *Knoxville*  
Kenneth Tonahill, *Millington*  
Robin Welsh, *Memphis*  
Heather Marie Wilson, *Loudon*  
Marsha Wilson, *Antioch* ■

**For information or an application for next year's class, please contact:**

**Ned Andrew Solomon**  
**Director, Partners in Policymaking™**  
**Council on Developmental Disabilities**  
**Andrew Jackson Building**  
**13th Floor, Suite 1310**  
**Nashville, TN 37243-0228**  
**Phone: (615) 532-6556**  
**Fax: (615) 532-6964**  
**TTY: (615) 741-4562**  
**E-mail: ned.solomon@state.tn.us**



**Ned Andrew Solomon is director of the Partners in Policymaking Leadership Institute™ at the Tennessee Council on Developmental Disabilities.**

## Having Your Say on Election Day

By Lorre Mendelson

**T**ennessee Protection and Advocacy, Inc. (TP&A) is delighted to enhance our commitment toward voting opportunities in Tennessee for people with disabilities through a grant from the Tennessee Council on Developmental Disabilities. The next statewide Election is November 5, 2002.

Here are some voting facts for people with disabilities in Tennessee.

- Any citizen of the United States, who is, or will be, eighteen (18) years of age or older on

or before the date of the next election, and is a resident of Tennessee may register to vote, unless disqualified under the law. People who have a guardian or conservator are legally allowed to vote unless a judge has ruled that their right to vote has been removed.

- Qualified voters register to vote by obtaining and completing a voter registration form and filing the form with the local county election

*continued on the next page*

## Remembering Diane Holtsclaw

By Bill Shiers

**H**er friends called her Lady Di-, a nickname that communicated the love, respect, affection, and gratitude they had for the many ways she enriched their lives.

Diane Holtsclaw started her fourteen-year relationship with The Arc of Washington County in 1985. Her first job, while concurrently attending college, was secretary, although many thought her real job was: Director of Keeping-Things-Together-in-Stressful-Times.

Her first office in those early days was the garage of the Unaka Group Home, a step up from her humble beginnings as an employee of Dairy Queen.

At the time of her death, she was the Associate Director of Support Coordination, Respite, Home of Your Own, and Family Support Services.

Nourishing a reputation for compassion, caring, commitment, tenacity, loyalty to people with disabilities and their parents, and supporter of staff, Diane was the heart of The Arc of Washington County.

Staff and parents often sought her advice and counsel. When the going got tough, she was the kind of person who rolled up her sleeves and

asked, "How can I help?" She was a sensitive and generous friend to many and an inspiration to all. Diane was a person who brings out the best in others. When conflicts occur, she helped seek compromise and consensus. A deeply religious person, she demonstrated love and charity for everyone's point of view. She lived a life of unconditional respect for everyone.

She was quick to laugh and quicker to praise the efforts of

colleagues and staff.

People felt more worthy, valued, and respected in their associations with her. She was a person who elevates the human spirit. Diane was a person who makes a difference in the lives of all who are fortunate to know her. ■



Diane Holtsclaw

*Bill Shiers is director of The Arc of Washington County.*

commission. Registration may be in person or by mail. You must vote in person the first time if you register by mail. If you do not receive a card in the mail indicating you are registered to vote, call the local county election commission to learn how best to proceed, as you may not be registered.

- Registration forms may be completed at the local county election commission office, Department of Safety (motor vehicles division), Department of Health (WIC program), Department of Human Services, Department of Mental Health and Developmental Disabilities, Department of Veterans' Affairs, public libraries, county clerk's offices, and register of deeds' offices. Voter registration-by-mail forms may be obtained from the county elections commission office, the post office, and a variety of other public offices across the state.
- People who are homeless have the right to vote and may register utilizing locale and the post office or service providers for a delivery address.
- For early voting, there is a 15-day window, from 20 days to 5 days prior to the election.
- Those requesting an absentee ballot for every election need to have a Tennessee doctor complete a medical form. If you are requesting an absentee ballot, you need to do so 7 to 90 days before an election.
- To participate in an election, a qualified voter must be registered at least thirty (30) days before the election. ■

### **Important contacts in Tennessee include:**

**Brook Thompson**  
**Coordinator of Elections**  
**State of Tennessee,**  
**Division of Elections**  
**312 Eighth Avenue North, 8th Floor**  
**William R. Snodgrass Tower**  
**Nashville, TN 37243**  
**Telephone: 615/741-7956**  
**Brook.Thompson@state.tn.us**  
**Website:**  
**[www.state.tn.us/sos/election.htm](http://www.state.tn.us/sos/election.htm)**

**Tennessee Protection & Advocacy, Inc.**  
**1-800-342-1660**  
**Website: [www.tpainc.org/](http://www.tpainc.org/)**

**Tennessee Disability Coalition**  
**615/383-9442**  
**Website: [www.tndisability.org/](http://www.tndisability.org/)**

The Tennessee Disability Voters meets monthly in Nashville to review voter education and voter registration activities. The group is developing a packet of nonpartisan materials for use by local groups in their own voter campaigns.

Tennessee Disability Voters was a co-sponsor of the first gubernatorial debate held in Nashville in August.

If you or your organization would like to become a member of Tennessee Disability Voters, please contact the Tennessee Council on Developmental Disabilities, Andrew Jackson Building, 13th floor, 500 Deaderick St., Nashville, TN 37243-0228. Telephone (615) 532-6615, TTY (615) 741-4562, FAX (615) 532-6964.

Editor: Mr. Jim Summerville  
 Contributing Editor: Dr. Jan Rosemergy  
 Graphic Design: Ms. Kylie Beck

### **About the Council:**

The Tennessee Council on Developmental Disabilities provides leadership to ensure independence, productivity, integration, and inclusion of individuals with disabilities in the community through promotion of systems change.

The editor will consider for publication original contributions, including news and feature stories, short fiction, poetry, artwork, and photographs but reserves the right to edit or decline publication. Brief letters to the editor are also welcome. Opinions expressed in any published matter are the author's and not necessarily those of the Tennessee Council on Developmental Disabilities or its staff.

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*Lorrie Mendelson is project manager of the Tennessee Voter Empowerment Project for People with Disabilities at Tennessee Protection and Advocacy.*

The Council Office has moved! See our new address below.

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For more information about the Council, contact the Council office at the Andrew Jackson Building

500 Deaderick Street, 13th floor, Suite 1310, Nashville, TN 37243-0228

Telephone (615) 532-6615 • TTY (615) 741-4562 • Fax (615) 532-6964

E-mail [tnddc@state.tn.us](mailto:tnddc@state.tn.us) • Web site [www.state.tn.us/cdd](http://www.state.tn.us/cdd)

Vanderbilt University  
John F. Kennedy Center  
Peabody Box 40  
230 Appleton Place  
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